

# PBSCT PATIENTS' GUIDE

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As a peripheral blood stem cell transplantation (PBSCT) patient, you are the most important member of your medical team. Throughout your care, the doctors and nurses at Clearview will be talking with you about what will happen during your PBSCT and will be sharing a lot of information with you, much of it in probably unfamiliar terms.

In this Patients' Guide, you will find a general outline of the phases and procedures that accompany a PBSCT program, as well as a brief introduction to the biology behind this treatment.

Knowing what to expect will make things a little easier for you throughout your transplantation experience. Everybody at Clearview is there to support you and give you what you need. We will be ready to help you every step of the way!

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## Stem Cells

The Clearview Cancer Institute of Huntsville, Alabama has initiated a Peripheral Blood Stem Cell Transplantation (PBSCT) Program to provide this treatment option to the patients of northern Alabama and south-central Tennessee. The transplant program at Oncology, PC, is one of the first 100 transplant programs in the United States to receive national accreditation by the Foundation for the Accreditation of Cellular Therapy (FACT).

PBSCT may be used to treat eligible patients with leukemia, lymphoma, or multiple myeloma. High-dose chemotherapy is sometimes the best way to treat certain types of cancer because high doses of anti-cancer drugs destroy more tumor cells. Unfortunately, these drugs also kill other cells in the body such as stem cells. These stem cells (formed in the bone marrow) are the “mother” cells to all other types of blood cells. If these stem cells are unable to produce adequate numbers of red blood cells (RBCs), white blood cells (WBCs), and platelets, a patient can die from infection and/or bleeding. To rescue a patient from this, stem cells are taken from the bloodstream before chemotherapy, frozen, stored, and then infused after chemotherapy is complete. Generally, after approximately seven to fourteen days the infused stem cells will begin reproducing RBCs, WBCs, and platelets, sending the patient well on the way to recovery.

## Bio 101: How Your Body Works

Let's first talk about how your body works and the functions that your organs perform. This will help you understand the important part each organ plays in the day to day function of your body.

### Bone Marrow

Bone marrow, located in the center of your bones, is the place where blood cells are made. Usually just the flat and long bones are responsible for the production of blood cells. These blood cells (called stem cells) are produced in the marrow and mature to become your red blood cells, your white blood cells, and your platelets. These cells are then released into the blood where they perform the following functions:

- *Red blood cells - carry oxygen from the lungs to body tissues*
- *White blood cells - fight infections or provide defense against infections*
- *Platelets - form clots, which stop bleeding*

### Immune System

Your immune system is made up of white blood cells, the thymus gland, the spleen, and multiple lymph glands. This system helps your body both to fight off infection and to recognize tissues which are not your own.

When you receive a bone marrow transplant, we temporarily “turn off” your immune system with radiation and chemotherapy so that your immune system will not react to your transplanted bone marrow as something foreign.

### Heart

Your heart pumps blood through the body so that oxygen and nutrients are carried to all parts of your body.

### Lungs

The lungs are the place where oxygen attaches to the red blood cell. The lungs help to ensure that the proper balance of oxygen and carbon dioxide is present in your body.

## **Liver and Kidneys**

As your body works each day, waste products are made that must be removed. Your liver and kidneys are responsible for monitoring the blood for these products and removing them. Certain medicines can also build up in your body and must be filtered or removed from the bloodstream.

You can see that each of these organs plays a vital role in your body's daily activity. If one of them is not working properly it can effect your body's ability to rebuild after receiving chemotherapy.

## **Blood Counts**

As we mentioned earlier, there are 3 types of blood cells (all of which originate from the stem cells): red blood cells, white blood cells, and platelets.

### **Red Blood Cells**

The red blood cells carry oxygen, so if the number of red blood cells is decreased (anemia) you might be short of breath, tired, weak, and pale. We call the red blood cell count the packed cell volume or hematocrit (hct). The usual value is 37-47%, however, a hematocrit of 26 or greater would be acceptable for someone who has previously had chemotherapy. If your hematocrit falls too low your doctor will order a transfusion of red blood cells for you.

When your red blood cell count is low, there are a few things that you can do to conserve your energy. First, spread your daily activities so that you can arrange frequent rest periods between activities. Secondly, don't try to move too quickly from one position to another. If you are lying down, slowly sit up, and after sitting a minute, stand up. If you move too quickly you might get dizzy and lose your balance.

### **White Blood Cells**

White blood cells (WBCs) fight infection or help provide defense against infections. A normal WBC count is 4,000 to 10,000. Granulocytes are one kind of white blood cell. When we are referring to your ability to fight infection, we are concerned with the number of granulocytes that you have. "Segs" and "bands" are the names of the granulocytes which are mature and effective in your fight against infection.

We can calculate your absolute granulocyte count (AGC) . This tells us the number of mature "fighters" that you have. Each day when your blood counts come from the lab, the report will include how many of each type of white blood cell that you have (differential). We will add the percentage of "Segs" and "bands". Next, take that percentage times the total WBC count to calculate your AGC [(Segs + Bands) x WBC]. This tells us about the recovery of your bone marrow as well as your body's ability to fight infection. It is important for you to monitor your body for signs of infection. If you notice any of the following you should alert your nurse right away: fever; pain, redness, tenderness or swelling anywhere on your body; chills; burning when using the bathroom; diarrhea; cough; runny nose; or drainage from any part of your body. We will also monitor you closely, but to be most effective we need your help.

Medications called growth factors such as Neupogen are usually used in an attempt to accelerate your white blood cell recovery.

### **Platelets**

Platelets are the blood cells which help to form clots. If your platelet count gets too low, you may have some bleeding. Your doctor and nurses will examine you daily in an attempt to locate any evidence of bleeding while your blood counts are low. We also ask that you keep an eye on yourself. Frequently, the patient is the first to notice any signs or symptoms of bleeding. You should look on your skin for any bruises or small purplish spots called petechiae. Petechiae are caused by small breaks in the capillaries under the skin. Any bleeding from your gums,

nose, rectum, bladder, or when coughing must be reported. Women should report any menstrual bleeding even if you think it is time for your period. The development of a headache or blurred vision should be reported also. If you develop nausea or a cough, you should report this to your nurse so that you can get some medication. Throwing up or forceful coughing could increase the pressure in your small vessels and cause a break in the vessel. We would like to prevent this if possible. The normal platelet count is 150,000 to 420,000. However, your platelet count will have to get very, very low for there to be any bleeding. If your platelet count gets too low, your doctor may order a platelet transfusion.

## Phases of Care for PBSCT Patients

Listed below are the phases of care of the PBSCT program. They are listed in the order in which they occur to help you understand when things will happen.

- » **1. Consultation** - History and Physical: review records, x-rays, and pathology; discuss treatment options focusing on role of PBSCT; phone and written report to referring MD. This appointment takes approximately one hour for the initial consultation. After the evaluation phase is completed, an additional one hour consultation occurs to review results of evaluation studies.
- » **2. Evaluation** - Studies to confirm eligibility appropriateness, risk and evaluability, donor/source selection, confirmation of insurance coverage or other arrangements for entire program including both inpatient and outpatient services. This phase takes several weeks to complete.
- » **3. Preparation** - Scheduling and planning of placement of central venous catheter collection and processing hematopoietic stem cell source, high dose conditioning chemotherapy (sometimes inpatient). This phase takes several weeks to complete.
- » **4. Transplantation** - Infusion of stem cells. The process of infusion of stem cells takes usually only 4-6 hours.
- » **5. Inpatient Care (Recovery)** - Supportive care until discharge. Average inpatient stay approximately 7 days.
- » **6. Intensive Outpatient Care** - Continuous nursing and physician supervision, frequent laboratory and infusion therapy requirement (blood, platelets, antibiotics and/or other supportive care extends to 30 days post-transplant).
- » **7. Long-Term Care** - Disease monitoring, complications follow-up, and revaccination. Requires periodic visits to transplant MD over a 2 year period.

## Patient Evaluation

One of the first things you can expect is a meeting with the PBSCT coordinator, whose job is to arrange insurance benefits. Unfortunately, you cannot assume that your medical insurance will automatically cover all the expenses involved in your transplant. With the current emphasis on medical cost-containment, some insurance companies are rejecting PBSCT claims; other companies will pay for PBSCT as treatment for some diseases, but not for others. The payment situation is improving as PBSCT becomes increasingly recognized as an effective treatment for so many diseases. The PBSCT coordinator or the business office can assist with your insurance questions.

The next step in the process is to schedule some tests that must be done before the transplantation. These tests may be repeated during and after your treatment to see how your body is doing. Before treatment begins, your disease will be evaluated and an assessment made of some of your organ functions, such as the heart, lungs, liver, and kidneys. These are done by a series of standard blood and x-ray tests to make sure you are physically healthy enough to withstand the stress that the transplant will put on your body. Most of these outpatient tests do not require preparation. We view these tests as fact-finding procedures to help you and your family make informed decisions. The tests may include:

- » **MUGA Scan:** This test measures how well your heart can pump blood through your body. A special dye will be administered through an injection into a vein. Shortly after the injection of the dye, the dye will enable us to take “pictures” of your heart while you are lying down. This test takes about 90 minutes. (MUGA or ECHO will be performed.)
- » **Echocardiogram (ECHO):** This is a noninvasive and painless procedure which looks at the structures inside your heart and blood flow through your heart. You will lie flat approximately 10-15 minutes while an instrument is placed at different locations of the left side of your chest near your heart.
- » **Electrocardiogram (EKG):** This painless, noninvasive test tells your physician about the electrical activity of your heart. It involves putting sticky pads with electrodes on your arms, legs, and chest. You will lie still on a flat bed for about 10 minutes during the test.
- » **CT Scan (CAT Scan):** Depending on the type of cancer you have, you may need a CT scan. The CT scan can show us areas where your cancer may be. During this painless test, you will lie flat on a table that moves through a doughnut-shaped x-ray-like machine. A special dye may or may not be used. This procedure may take a long time to get the correct pictures, but it is important that you do not move.
- » **Pulmonary Function Test (PFT):** This test is done to determine the amount of air taken into the lungs with each breath, the amount of air that is let out or exhaled, and the speed at which it is exhaled. This test helps the physician determine whether there are any abnormalities in your lungs prior to transplant.
- » **Chest x-ray:** An x-ray of your chest will be taken to look for abnormalities in your lungs. During this painless procedure the x-ray technologist asks you to take a deep breath and hold it for a few seconds while the x-ray is being taken.
- » **Blood Tests:** Blood samples will be drawn to determine if your liver, kidneys, and bone marrow are functioning properly. Your blood will be tested for previous infections and prior exposure to certain viruses (e.g. HIV and hepatitis). Your blood will also be tested for your blood type and clotting ability. Other tests may be performed as needed.
- » **Bone Marrow Aspirate and Biopsy:** You may need to have a bone marrow aspirate and biopsy to evaluate your bone marrow for cells and any evidence of disease. This procedure is performed by putting a large bore needle in the back of your hip bone. This is not considered an operation so you will not be put to sleep. A local anesthetic will be used to numb the site. A syringe is then attached to the needle and a sample of your bone marrow is withdrawn for a bone marrow biopsy. A small piece of bony tissue is taken from the hip bone.

- » **Creatinine Clearance:** Your kidneys play a major role in ridding your body of the chemotherapy you will be given. To determine if they are functioning properly, you will be asked to collect your urine for 24 hours. You will be given a special container for this test and it should be kept on ice or refrigerated.
- » **Psychosocial Assessment:** The social worker will do an assessment to ensure that you are emotionally capable of withstanding the psychological stress of a transplant, that you have sufficient social supports, and that you are likely to be compliant with your medical regimen before, during, and after the transplant.
- » **Nutrition Assessment:** The dietitian will establish your general nutritional status. She will assess your food likes and dislikes. Knowing your dietary preferences will help us maintain your nutritional balance.
- » **Dental Exam:** We will ask your family dentist to perform a routine exam and address any problems before your PBSCT procedure begins. This is preventative.

## Pheres-Flow Catheter

Before your stem cells are removed, a special plastic catheter, called pheres-flow, will be inserted. This catheter will be placed into a large vein in your shoulder and will be used to remove your stem cells, draw blood, give chemotherapy and fluids, and for blood transfusions. This is an outpatient procedure that will be done in the radiology department. Local numbing medication will be given prior to the placement of the catheter. The pheres-flow catheter will remain in place until you are discharged from the hospital, or you may go home with it if your doctor decides you still need medication through it.

On the morning of your catheter insertion, you will go to the department of radiology at Huntsville Hospital to have the catheter placed. Family members may accompany and wait for you there. You will need someone to drive you home after this procedure. You may use Tylenol or Advil if you have any discomfort from the catheter.

### The Procedure

Autologous peripheral blood stem cell patients will have a triple lumen pheres catheter. You will have this catheter coming out of your body on your chest. The radiologist will make a small incision in the area of your shoulder and put one end of the catheter into a large vein called the superior vena cava. It is threaded through this vein until it reaches your heart. The other end of the catheter is threaded under the skin for a couple of inches and brought out through a small incision in your chest. This incision is called the exit site. You will have a chest x-ray to ensure that your catheter is in the proper location.

Your Clearview nurse will teach you how to clean the exit sites and how to keep the blood in the tube from clotting. Do not take tub baths until your catheter site is healed (about 3 weeks). This catheter should not upset your daily routines. Bathing, showering, exercise, housework, sex, and sleeping are safe as long as the tube is carefully taped to your chest. Before you engage in any hard physical work, discuss your plans with your nurse or doctor.

If you should have excessive bleeding, pain, shortness of breath, or swelling in either of your arms, please call (256) 705-4224 to report this.

### What is a Pheres-Flow Catheter?

A catheter is a long, flexible, hollow tube made out of silicone. Silicone is a soft but strong substance similar to rubber. Fluids such as blood, medications, or nutritional liquids can flow easily through the catheter's hollow tubes (lumens). The Pheres-Flow catheter is a special catheter because it contains three hollow lumens which

are wrapped together inside of the catheter's canula. From the outside it appears that the three extension legs (lumens) join together to form a single, hollow tube within the canula. However, they remain separate throughout the entire catheter. Each hollow tube has a different colored plastic clamp and a special cap on the end of the extension leg to close off the opening when it is not needed.

### **Why do I need a Pheres-Flow catheter?**

You may have already been receiving medications and blood products into your blood stream. You may also have been providing blood samples to your doctor. This is most commonly done by inserting a needle into a small vein in your hands or arms to allow for the injection of medications or the removal of blood for samples. Your doctor may have determined that you will require large volumes of blood products or medications to be administered, or frequent blood samples withdrawn. A catheter placed in a large vein close to the heart enables medications to move quickly through your body and lets blood be withdrawn without constantly reinserting needles into your veins. The Pheres-Flow catheter is also very durable and can be used for many months.

### **Pheres-Flow Catheter Care**

There are several tasks you must learn in order to care for you Pheres-Flow catheter at home. These include: flushing the lumens, changing the dressing, and changing the caps.

### **Flushing the lumens for the Pheres-Flow catheter**

In order to prevent clots from forming in the lumens of the catheter, you will be expected to flush the catheter three times a week (Mon, Wed, Fri) with 10ccs of sterile normal saline. Also flush if you see blood in the catheter.

### **Supplies you will need:**

- 1. Anti-bacterial soap to wash your hands.*
- 2. One alcohol pad for each lumen of the catheter.*
- 3. One 10ccs syringe of saline for each lumen of the catheter (use a 22 gage 3/4 inch needle)*

### **Steps in the flushing procedure:**

- 1. Wash your hands thoroughly with warm, soapy water.*
- 2. Be sure the clamps on all of the catheter lumens are unclamped (open).*
- 3. Wipe the cap of one lumen with an alcohol pad.*
- 4. Take the needle cap off of the syringe of saline, and without touching the catheter's extension leg injection cap, insert the needles into the lumen injection cap.*
- 5. Gently flush, in one steady push, the saline solution from the syringe into the lumen.*
- 6. Reclamp the lumen while you are still pushing down the syringe. If possible try to clamp while there is still a small amount of solution left within the syringe (1-3ccs of saline).*
- 7. Repeat steps 3-6 for each of the other lumens. Use a fresh alcohol pad for each lumen.*

**For patients who do not have prepared syringes of saline, the following supplies will be needed: Normal Saline (NS) vials, 30-50cc/vial; Alcohol wipes; 18G and 22G 1 inch needles; 10cc syringes.**

**To flush out the lumens of the catheter, these steps must be followed:**

1. *Wipe the top of the NS vial with an alcohol wipe. Wipe for approximately 30 seconds.*
2. *Connect the 18G needle to the 10cc syringe. Do not touch the ends of the syringe or needle with your hands.*
3. *Carefully remove the needle cap and insert the needle into the center of the cleaned top of the vial of NS.*
4. *Withdraw 10cc of NS from the vial into the syringe.*
5. *Carefully remove the 18G needle from the syringe and discard into the provided biohazard needle container.*
6. *Place the 22G needle on the syringe filled with NS, being careful not to touch the ends of the needle or syringe.*
7. *Follow steps 2 through 7 of the instructions “Steps in the flushing procedure.”*

**Changing the dressing of the Pheres-Flow catheter**

In order to keep the skin around the catheter clean and reduce the risk for infection you will be asked to change the dressing on a regular basis. The frequency of the dressing change is every Monday, Wednesday, and Friday. It also depends on the condition of your skin, your susceptibility to infection, the type of dressing being used, and other factors. Always change the dressing if it has become wet, dirty or loose no matter what the scheduled routine is.

Dressing supplies will be determined by your doctor or nurse. The type of supplies used depends on the condition of your skin and what is available at your health care facility. However, there are some general principles of dressing change that will apply no matter what supplies you are using.

**Supplies you will need:**

1. *Anti-bacterial soap to wash your hands*
2. *Skin cleaning supplies such as alcohol or betadine swabs, and possibly an anti-bacterial ointment*
3. *A transparent dressing, gauze and tape dressing, or large Band-Aid dressing*

**Steps in the dressing change procedure:**

1. *Assemble supplies on a clean work area.*
2. *Wash your hands thoroughly with warm, soapy water and dry them completely.*
3. *Take off the old dressing by peeling it down in the direction of hair growth. Do not touch the catheter exit site.*
4. *Check the exit site for redness, drainage (such as pus or blood), swelling, or tenderness. If you notice any of these signs of infection, call your doctor.*
5. *Wash your hands again.*
6. *Using the skin cleansing supplies provided, such as alcohol or betadine swabs, clean the skin. Start at the exit site and move outward in a circle until you have cleaned at least two inches of skin all around your catheter. Do not let the swab touch the exit site again. Repeat this procedure with all the cleansing supplies provided. Allow the skin to dry completely.*
7. *Gently clean the outside of the catheter (all 3 lumens) with an alcohol wipe, starting from the exit site to the catheter end. You may hold the catheter at the exit site with another alcohol wipe to prevent pulling on the catheter. Do not pull on the catheter.*
8. *If you are using an anti-bacterial ointment, place a small amount directly on the exit site.*
9. *Place the pre-cut gauze dressing over the exit site, fitting it snugly around the catheter.*
10. *Apply the selected dressing directly over the exit site of the catheter. Check to make sure the catheter is not kinked underneath the dressing. The dressing should be occlusive.*
11. *You may need to secure the dressing with extra tape to be sure that it does not come loose easily.*
12. *Always secure the catheter in such a way that you can easily see the cap ends.*
13. *Note: Do not use scissors or any sharp-edged instruments as they could damage the catheter.*

### **Changing the caps of the Pheres-Flow catheter lumens:**

The caps on the catheter lumens should be changed with each dressing or a least once a week. Supplies you will need:

1. *Anti-bacterial soap to wash your hands.*
2. *One alcohol pad for each lumen of the catheter.*
3. *One new twist-on cap for each lumen of the catheter.*

### **Steps in the cap change procedure:**

1. *Wash your hands thoroughly in warm, soapy water.*
2. *Be sure the clamps on all of the catheter lumens are clamped.*
3. *Twist off the cap of one lumen and clean the opening with an alcohol pad.*
4. *Twist the new cap firmly onto the lumen*
5. *Repeat steps 3-4 for each lumen of the catheter. Do not over twist. Tape the connection. Use a fresh alcohol pad for each lumen.*
6. *Note: Remember to close the clamp each time the system is opened and always have a clamp available for emergencies.*

## **Mobilization of Stem Cells**

Before collecting your stem cells you will be given a growth factor, called granulocyte-colony stimulating factor (G-CSF). This is a medication that helps your body make white blood cells. G-CSF is injected into the layer of tissue under the skin for several days prior to the collection of your stem cells. The purpose of giving you G-CSF is to move the stem cells that are stored in your bone marrow to your blood stream where they will be removed for later uses. When your white blood cell count is rising, the stem cells from your your blood is then ready to be collected.

You and your caregiver (family or friend) will be taught by your nurse to give G-CSF. Calcium supplements will also be given for several days before your stem cells are removed to help prevent calcium loss during the stem cell collection. You are encouraged to increase your dietary intake of calcium-rich foods if tolerated. Dairy products such as milk, yogurt, and cheese are primary sources of calcium. Other sources of calcium include dark, leafy vegetables and calcium-fortified foods such as fruit juices and breakfast cereals. You must restrict your dietary intake to low fat foods during your course of treatment.

Bone aches and pains are expected side effects from G-CSF and may be treated with Tylenol.

## **Peripheral Stem Cell Collection**

### **The Pheresis Process**

Stem cell collection is performed at Clearview by registered nurses. You should eat a good breakfast the day of the procedure and bring a sack lunch, or you may send a family member to obtain lunch for you.

Sterile tubing is connected from your Pheres-Flow catheter to the pheresis machine which separates the stem cells from the other blood cells. The machine will retain the stem cell portion of your white blood cells. All the rest of the blood will be returned to you. This apheresis machine is kept in a special room where you will have the apheresis done. You will be attached to the machine for three to four hours at a time. There will be a nurse present the entire time. This nurse has special skills to run the machine and to take care of you.

After your stem cells are collected they will be taken to the bone marrow processing laboratory. Your stem cells will be examined to find out how many actual stem cells were obtained. The harvesting process will be done every day until enough stem cells have been collected, usually 1-3 days. In the laboratory, the stem cells will be mixed with some of the plasma from your blood that was obtained when your stem cells were collected. The stem cells will then be mixed with a freezing solution and a substance that will preserve them, called DMSO. The stem cells will be placed into equal parts that will each measure about one-half cup. The cells will then be placed in a special freezer and will remain frozen until time for transplantation. This is called cryopreservation. Prior to the freezing, samples of your stem cells will be checked to see if they can survive and that no germs are growing in them. They will later be thawed and infused through your pheres-flow catheter on Day 0 (*transplant day*).

While connected to the apheresis machine, you might temporarily feel a slight dizzy or lightheaded feeling when the blood is being withdrawn. The medicine used to keep your blood from clotting in the apheresis machine can make you feel cold or have numbness or tingling around your lips and fingertips due to low calcium. This can usually be controlled with calcium given orally (*Tums, taken as needed*) or intravenously, if severe. Other electrolytes (*chemicals in your body*) will be replaced as needed. Extra blankets can help with the coldness. Rare allergic reactions to the chemicals in the tubing may cause wheezing, hives, or itching. If this occurs, it can usually be treated with steroids or antihistamines. If too many platelets or blood clotting cells are withdrawn, bleeding can occur. Therefore, your platelet count will be monitored. Platelet transfusions will be available, if needed. You must sit relatively still in a reclining chair or hospital bed for the duration of the procedure, which can be uncomfortable. Your vital signs will be taken before, during, and after the procedure. During this procedure, you can watch television, listen to music, read, or rest.

### **A Word on Transfusions**

It is likely that you will need transfusion of red blood cells (*RBCs*) and platelets (*PLTs*) when your blood counts are low. The red blood cells carry oxygen to all the cells in your body, and without enough RBCs you have anemia. Anemia can make you feel weak, dizzy, short of breath, or chest pain. Hemoglobin is in your RBCs and carries the oxygen. The amount of hemoglobin is what we look at to decide if you need transfusion of RBCs. Normal hemoglobin is 12-16. When your RBCs are low there are some special precautions you need to take:

- Rest for 15-20 minutes between activities.
- Move slowly from a lying position to a sitting, then standing position so that you do not get dizzy.

The platelets assist with blood clotting, in other words, they help stop any bleeding. If your platelet count is low, you will be given a platelet transfusion. Normal platelet count is 150,000-350,000. Precautions to take when your platelet count is low:

- Use an electric razor rather than a blade razor.
- Use toothettes for mouth care and avoid hot foods or liquids that may injure your mouth.
- Avoid blowing or picking your nose. If you have a nosebleed, call your nurse right away.
- Let your nurse know if you notice any of the following: tar-colored or red urine; black and tarry or bright red bowel movements; blood in the material you cough up or vomit; headaches.
- Wear shoes or firm slippers every time you get out of bed.

The nurses and doctors will also take precautions to keep you safe, but you can help by being careful.

You will not be given transfusions of white blood cells when your WBC count is low because a WBC transfusion only boosts the WBC count for a few hours. You will be given G-CSF to help your WBCs recover.

## Chemotherapy

The last step in the preparation phase of care for PBSCT is receiving conditioning chemotherapy.

Conditioning chemotherapy is the term used for the high-dose chemotherapy you must receive before your peripheral blood stem cell transplant. The chemotherapy will be given over 2-7 days in order to destroy the remaining cancer cells. The chemotherapy may begin within one week after apheresis.

You will receive a combination of the following drugs: Busulfan, Cytosan, and Etoposide or Melphalan. Busulfan is a pill or IV form of chemotherapy that will be given two times a day for a total of four days or eight total doses. Cytosan will be given through the veins daily for two days. Etoposide will be given through the veins in a four-hour infusion daily for three days. Etoposide may be eliminated from your treatment if the PBSCT Medical Director feels that your physical condition necessitates this. If your transplant physician determines your physical condition warrants, he may choose to treat you with the IV chemotherapy agent Melphalan given for one hour on two days instead of Busulfan, Cytosan, and VP-16.

### General Side Effects of Chemotherapy

Large doses of chemotherapy destroy abnormal tissue cells, but they also effect normal cells of the skin, hair, and digestive tract – this causes some severe side effects. Some are permanent and others are only temporary. We will be with you to make you as comfortable as possible and to answer any questions you may have.

You may feel weak and tired. Most patients experience some degree of nausea and possible vomiting after receiving chemotherapy. Anti-nausea drugs are available to help relieve these side effects. Almost all peripheral blood stem cell transplant patients experience some hair loss, fever, mouth sores, and diarrhea – these are all temporary. Another side effect is swelling of the “parotids” (a bit like mumps) which are the glands on either side of your neck. This may hurt a little, and cause a hoarse voice, but will go down in one or two days. Bleeding and infection can also occur soon after the chemotherapy treatments. More serious problems which may occur later on can affect your lungs, liver, kidneys, and bladder. But we can usually prevent these problems from developing, or at least treat them if they do.

After receiving 2-7 days of chemotherapy, you may have about 1-2 days of rest before receiving your peripheral blood stem cell transplant or you may have the transplant the next day. The schedule will depend on the way your treatment is set by your doctor.

## Transplant Day

After your high-dose chemotherapy and brief rest period (about 1-2 days), you will receive your peripheral blood stem cell transplant - the actual infusion of your stem cells. This is the day you have been waiting for. You will be examined carefully by the nurse and doctor on the morning of the transplant. Before you receive your stem cells back, you will receive some medication through your IV line to help prevent any side effects and to help you relax. Your own previously harvested stem cells will be brought, frozen, to your bedside. Each bag will be thawed before it is infused through your Pheres-Flow catheter, as if you were receiving a blood transfusion. The stem cell transfusion looks like blood, only thinner and less red.

You may be aware of an odor and taste similar to that of garlic as the stem cells are infused, and it may cause you to feel suddenly nauseated and possibly, to vomit. It is not the stem cells that cause that reaction, but rather the chemical DMSO that is used to preserve the stem cells. The nausea will probably clear rapidly, but the odor

may persist for a day or so. If you are feeling sick to your stomach, tell your nurse. You can be given something to make you feel less sick. Sometimes sucking on hard candies helps diminish the taste and nausea associated with the stem cell infusion. Nurses will be at your bed when you get the stem cells back. Doctors will be available if needed. Your vital signs will be taken before and after your stem cell infusion. During this time, you can watch television, listen to music, read, or rest.

Signs of infusion-related reactions are: brief nausea or vomiting, garlic taste and smell, cough, shortness of breath, tightness in the chest, slow heart beat, high blood pressure, flushing, abdominal cramping or diarrhea, fever, and an increase in body fluids. Your urine will turn red at first as red blood cells are excreted by your kidneys. This is to be expected. IV fluids will be given to help clear your urine. Each bag of stem cells will be infused over 5-10 minutes. You will be at Clearview between 4-6 hours for the stem cell infusion.

Since the stem cells were collected prior to the conditioning therapy and given back to you after all the chemotherapy has ended, the transplant stem cells will not be damaged by the chemotherapy. Therefore, by giving you back your stored stem cells, we are giving you stem cells that your bone marrow will use to make new blood cells.

It is natural for you to feel both excited and scared on transplant day. You may think about having a successful transplant and about all the positive things in your future. But you may also worry about the negative things that could go wrong. Please share these feelings with those who can help— whether family, friends, and/or hospital staff. The social worker or the psychosocial coordinator is also a good resource for dealing with these issues. You and your family may feel somewhat “let down” right after the transplant procedure has been completed. There were no fireworks and you did not feel any different. This is a normal feeling that many transplant patients express.

## Recovery

Once you have had your transplant, a critical period of waiting begins. The high-dose chemotherapy that you underwent before your transplant severely depleted your body’s blood cells and disabled your entire immune system.

Based on your physical condition and blood counts, your physician will determine the appropriate time for hospital admission. However, most patients stay outpatient for several days post-transplant. If you have a fever of 100.5 degrees Fahrenheit or need supportive care, you will be admitted to the hospital. The average patient is in the hospital for 7 days. Once your blood counts begin to show recovery and your other symptoms are controlled, you will be able to go home. At this time you will maintain restrictions on diet and activities as determined by your physician. Clinic visits continue as determined by the transplant physician. At 6 months you begin revaccination of childhood diseases. You must wear your ID bracelet for 1 year post-transplant.

At approximately 100 days post-transplant your disease will be re-evaluated to assess the effectiveness of the PBSCT.

## VACCINATION GUIDELINES

Time After PBSCT	Vaccination	Comments
6 months (w/no GVHD)	DtaP (Diphtheria- Tetanus-Acellular Pertussis) Polio (inactivated) Hib (Haemophilus b) Hepatitis B (series) Pneumovax	No Sabin Polio virus (OPV) post PBSCT for patients or family members.
8 months	Dtap (Diphtheria-tetanus-Acellular Pertussis) Hib Polio (Inactivated) Hepatitis B (dose #2)	If Hep C+, check Hep A antibody. If Hep A antibody negative, give Hepatitis A vaccine.
12 months	Hepatitis B (dose #3)	
24 months (w/no CGVHD)	Immunize with MMR	No patients should have the MMR until 2 years post PBSCT. They must not be receiving active immunosuppressive medications and not have active GVHD. Family members may receive MMR.

## Visitor Guidelines

Infection control on the Oncology unit is very important. Patients in the unit are myelosuppressed and are unable to fight infection. The following guidelines are to help minimize the germs in the environment.

- Visiting hours are noon to 9:00 pm daily.
- Each patient may have two visitors in the room at one time. Other visitors may wait in the “day room,” located on the floor.
- One person may spend the night. The social worker can help find lodging nearby if other family members want to stay in Huntsville.
- We may limit visitation during certain periods of time during your transplant. If you become very ill, new visitation rules will be discussed with you and your family.
- The day room is provided for use by families of all patients on 7 East.
- Please do not take coats or other outer clothing into the patient’s room.
- All patient’s meals must be prepared by hospital staff. Only water provided by the nurse should be given to the patient.
- Family members are not to eat or drink anything from the patient’s tray.
- All meals for family members should be prepared and eaten in the lounge. Clean up is everyone’s responsibility.
- All visitors will need to check with the nurse and fill out a visitor illness questionnaire before entering the room. All visitors will be screened for presence of or exposure to infectious diseases. Any family or visitor who is not feeling well should not come to the hospital to visit. Persons who have not had chicken pox but have been exposed to this illness within the past 3 weeks will not be allowed to visit.
- Other symptoms of infection that prohibit visitation include:
  - + *fever, boils, blisters, shingles, cough, diarrhea*
  - + *cold sores, common colds*
  - + *sore throat, flu, bronchitis, eye infection*
- Visitation by children is strongly discouraged because children are exposed to many viruses from playmates and school mates. However, children under 12 may visit with permission from the nurse prior to each visit. Please consider the infection risk of your loved one and the other patients when requesting visitation by your children. You will be asked if the child has been exposed to any contagious illness, such as chicken pox or measles. In addition, if the child attends school or day care you will need to determine if other children in your child’s class have infections. Once you have discussed the situation with the nurse, then the child may be allowed to visit. The child must be screened prior to each visit.
- Children must be current on all required immunizations for their age. Oral polio vaccinations should be delayed if the family member is scheduled for admission for transplant. Children who have already received an oral polio vaccination may not visit the patient until 30 days after the vaccination. Please check with the transplant physician if the vaccination was injected.
- Children (*or adults*) who have been exposed to chicken pox but have never had chicken pox may not visit the unit for 21 days after exposure.

## Home Environment

### Cleaning

Your home should be thoroughly cleaned and disinfected prior to your arrival home from the hospital. Air filters should be changed before you come home and then changed at least every twelve months. If the air is too dry, you may need a humidifier added to your system. Cool mist humidifiers are safe to use. Do not add oil or medicines to the water. The humidifiers should be changed and cleaned daily by your caregiver.

### Daily Hygiene

- Continue to bathe or shower daily using antibacterial soap. Do not use well water!! You should not be afraid to take a shower with the catheter in place; you just need to be careful. A piece of plastic should be taped over the dressing. You can shower as usual, being careful not to get excessive water in the area of the catheter. When you have finished showering, the dressing should be checked to see if it has become damp. If the dressing is damp, the dressing should be changed. Ask us before swimming.
  - **WASH HANDS! WE CANNOT OVERSTATE THE IMPORTANCE OF HAND WASHING. MANY INFECTIONS, BACTERIAL OR VIRAL, ARE TRANSMITTED BY HAND TO MOUTH OR BY HAND TO NOSE. YOU SHOULD WASH YOUR HANDS:**
    - + *Before eating (or preparing food)*
    - + *After using the bathroom*
    - + *Any time that hands have touched a soiled object*
- » **Remember:** When in doubt, wash! You should be able to sing the “Happy Birthday” song twice for adequate hand washing. It is also important for family and friends to wash their hands frequently. Commercial soap is fine, but family and visitors should wash their hands vigorously and change hand towels frequently (*or use paper towels for drying hands*). Germs can collect in damp towels.

### Gardening

Bacteria and fungi grow on plants, in their water and soil, causing infection. However, by the time you return home from the hospital, you should have enough immunity so that you won't need to remove your household plants. But you should avoid close and regular contact with your household plants for the first six months or so.

### Pets

Dogs and cats are more problematic than plants. They can carry infections that are potentially harmful to you. You should not clean up after your pets, especially avoiding boxes and all animal waste. If you have a cat, take it to the vet to be checked for toxoplasmosis. If your cat is positive for toxoplasmosis, please consult your doctor for further instruction. Avoid dressing or cleaning fish or animals.

### Nutrition

Your appetite may be slow to return to normal. You may need nausea medications even after discharge. Your doctor or nurse practitioner will prescribe this medication for you.

Chemotherapy may change the way some foods taste. This will resolve eventually. Start with small, frequent meals rather than three large meals. Drink at least 6 to 8 glasses of water or fluids daily. The dietician will consult with you regarding your special discharge diet to lower your risk of food-borne illness. Also, see the dietary guidelines listed in Living Well.

## Minor Cuts, Bruises, and Aches

- Cuts: Put a clean cloth or bandage on a cut or scratch and hold it there until the bleeding stops. Wash gently with soap and water. You can apply an antibiotic cream such as Neosporin or Bacitracin. Keep the area dry and covered for 2-3 days. Call your doctor if you develop a fever or the area becomes red, swollen, or weepy.
- Bruises: A low platelet count can cause easy bruising, bruising for no apparent reason, or bruises that take a long time to fade and disappear. You need to call your doctor if you notice bruises. If you fall or hit yourself and start to swell, put ice on the area and call the doctor.
- Aches: You may feel some aches and pains in your joints, bones, and muscles. If they last longer than a few days, let our doctor know. You can try warm or cold packs if your doctor suggests them. A heating pad may help, but do not sleep on it. Do not use skin ointment or lotion and a heating pad at the same time since this can cause burning of the skin.

### **Be very careful with the following products; they can irritate the skin:**

- *Mentholatum Rub and Cream*
- *Absorbine Junior*
- *Oil of Wintergreen*
- *Mentholatum Deep Heating Rub and Lotion*
- *Absorbine Arthritic*
- *Ben Gay Lotion, Ointment, or Gel*

## Daily Care

- Check skin daily for any new rashes, petechiae (small red/purple dots on skin), or bruises.
- Continue rectal care at home, especially if you have diarrhea. Women should wipe from front to back to avoid spread of infection. Do not use rectal creams or suppositories without first talking to your doctor or nurse practitioner. You may try sitting in a hot bath to ease the discomfort.

## Skin Care

Since your skin will probably be dry and flaky, it may itch. Try not to scratch. Let any scabs fall off by themselves; do not pick at them. Vaseline is cheap and works well for dry skin. If you like to use a lotion or cream, there are lots of choices:

- Aquaphor
- Carmol-10
- Corn Huskers Lotion
- Keri Light
- Lacticare
- Neutrogena body lotion
- Nutraplus
- Purpose dry skin creme
- Rose water and glycerin
- Wibi lotion

If you use another product that irritates your skin, check the label. Products that contain perfume, lanolin, or alcohol often cause problems. Most women wear Almay makeup without any problems. Introduce makeup and lotions one at a time, and observe for signs of allergic reactions. Use previously unopened makeup which is the same type/brand that you used prior to your transplant.

You can prevent blisters by wearing work gloves when you work in the yard or use tools. Protect your feet by wearing shoes that fit. Do not go barefoot inside or outside.

## **Sun Exposure**

Limit exposure to the sun since chemotherapy makes your skin very sensitive. Sit in the shade when possible during outdoor activities. Use sunscreen of at least SPF 25 to protect your skin (don't forget to protect your ears and the back of your hands). Remember to wear a hat, wig, or head cover until your hair grows back. Avoid direct sunlight for one year after your transplant. Use a lipstick (like Chapstick, Blistex, or Pre-Sun) with sunscreen if you spend much time in the sun.

## **Nails and Hair**

Your nails may look and feel different after your transplant. Be careful not to tear your nails or cut your skin when you are trimming your nails. Use an emery board for nail care. Cut your toe nails straight across. Women should use a polish remover that contains oil to keep the nails from drying out. Nails may become thin and fall off a few months after transplant.

Use a gentle "pH balanced" shampoo since your scalp will be very sensitive at first. A moisturizing cream rinse can help you manage the new baby-fine hair. Medicated and dandruff shampoos will be too hard on your scalp.

The American Cancer Society can provide wigs. Let the social worker or nurse know if you need more information about wigs. You can wear a hat, scarf, turban, or other head covering until your hair grows back.

## **Eyes and Ears**

You may have tired, dry, or gritty eyes because of your treatment. You can buy one of the natural tear products at the drugstore to help the dryness. Be sure you have a fresh, new bottle of your own. Do not touch the top of the bottle with anything after you have taken off the top. Call the doctor if your vision becomes blurred or you start seeing double. Do not use eye cups or any homemade eye solutions since this could cause an infection.

Wash your outer ear with a soapy wash cloth when you bathe or shower. You can use lotion if your skin is dry. Please do not use ear wax softeners or wax removal products from the drugstore. Do not put matchsticks, hairpins, pencils, cotton swabs, or sharp instruments in your ear. Call the doctor if you have ear pain, drainage, or any trouble hearing.

## **Oral Care**

- Continue your oral hygiene at home to ensure healthy teeth and gums and to prevent infection. Brush after meals and at bedtime.
- If your platelet count is greater than 50,000, a soft toothbrush may be used. Otherwise, continue to use sponge toothettes.
- Toothpaste may be used once you get home. If it burns your gums, you may need to continue with the biotene a while longer.
- Use your antifungal mouthwash after brushing as instructed per your PBSCT team.
- Do not use dental floss. Use Vaseline to keep lips moist.

- Let your doctor or nurse know before you schedule any dental work. Also, you should let your dentist know you have had a peripheral blood stem cell transplant.

## **Insect Bites**

Use a liquid or stick bug repellent when you are outside during the summer. Do not use a spray since it can bother your lungs. If you are bitten, keep the area clean and dry. Use calamine lotion to stop the itching. Call the doctor if the bites get red, swollen, or start draining. Do not use medicines from the drugstore like Solarcaine or Americaine to stop the pain. The creams may cause irritation and you will not know what is causing the redness.

## **Physical Activity**

- Having a peripheral blood stem cell transplant is physically stressful. Your energy and endurance will take some time to return to its previous level. There are some things which you can do to help recover your strength. Limit activity the first month of discharge. Space out your activities, allowing for rest periods in between; try not to over exert yourself. Light exercise every day is better than infrequent heavy exercise.
- Walking is a good form of exercise. Start slowly and limit your distance at first. Increase distance and pace once you begin to feel better. Easy jogging, bicycle riding, aerobics/calisthenics, leisurely tennis or racquetball, and even mild weight lifting are OK. No contact sports.
- Driving is allowed when your platelet count gets to 50,000. Check with your physician prior to making travel plans in the immediate post transplant period.
- Avoid swimming in public pools, lakes, rivers, and hot tubs while you still have your Pheres-Flow catheter. You are not allowed to stand or swim in stagnant water (*e.g. ponds, lakes*).
- Limit home visitors to close friends and relatives. Do not allow sick people to visit your home.
- For the first 6-12 months following the transplant, you need to avoid crowds, which limits the kinds of sports in which you may participate. You should avoid any sport that may cause injury or bleeding. Please consult us before beginning any exercise program.

## **Sexuality**

- You may resume sexual activity once your platelet count is 50,000.
- You may need to use KY Jelly/Replense (*water soluble*) for lubrication.
- The patient may receive but not perform oral sex.
- Condoms are not necessary if you have a monogamous partner. They are necessary if the partner has a history of genital herpes. Condoms should be lubricated.
- Although a transplant significantly reduces fertility in men and women, it is still possible for conception to occur. Talk with your doctor or nurse practitioner regarding birth control options.
- Remember you may be fatigued or have a decreased sexual desire while in the post transplant period.

## **Breathing Problems**

You can prevent breathing problems if you do not smoke cigarettes, cigars, or pipes, and stay away from those who do smoke. Try to stay out of smoke-filled rooms and other places where there is air pollution. Call your doctor if you develop a cough or become short of breath.

Remember to use a nasal spray such as Salinex or Ocean if your nose feels dry. Get a clean, fresh bottle of your own that no one else uses. (*Do not buy products for colds, allergies, or sinus problems*).

Call the doctor right away if you feel like you are getting a cold or flu. Do not try to treat it yourself. A sore throat, cough, or fever could mean you need medical treatment, not home remedies. You also need to let the doctor know if you have sinus pain or drainage.

## **Pain Relief**

Do not take aspirin or any product containing aspirin for pain relief. Aspirin can cause bleeding because it affects your platelets. Read the label of every pain-relief product to see if it contains aspirin or acetylsalicylic acid. Ask the pharmacist if you are not sure after reading the label.

Products containing acetaminophen (*Tylenol*) are OK to take for pain relief. The doctor may tell you to take an acetaminophen product for a fever.

## **Examples of products with acetaminophen that you can use are:**

- Allerest Headache Strength Arhralgen Aspirin Free Anacin 3
- Bancap Brom-Seltzer Datril
- Liquiprin Solution Percogesic Sine-Aid
- Sinarest Temptra Tylenol
- Valorin

## **Infection/Bleeding Precautions**

- Take your temperature daily at the same time each day. Take it more often if you are not feeling well.
- You should wear disposable rubber gloves if you must change a diaper.
- You may go to public places, but do so during down hours and slow times.
- Wash your hands after using the bathroom, petting animals, and before eating.
- Remember to avoid children who have received a live virus vaccine (*i.e. polio, chickenpox*) for three weeks after they have been vaccinated. Please ask your doctor if you are unsure if the vaccination is a live virus.
- If at any time you come into contact with a person who has chicken pox, shingles (*herpes zoster*), or measles, we need to know about this at once, even if it is only a remote exposure. If there is any viral or bacterial epidemic in your community, we need to know about that too.
- Do not use suppositories or enemas. You may need to change your diet or increase your exercise to resolve constipation.
- Avoid over the counter medications such as Aspirin, Ibuprofen, Advil, Goody's, or Alkaseltzer. These medications may cause bleeding.
- Blow your nose gently.
- Use an electric razor until your platelet count is greater than 50,000.
- Wearing a Face Mask: This is no guarantee against infection, but it may help guard against airborne bacteria and viruses. Generally, we encourage you to wear a face mask for the first three months after leaving the

hospital when:

- + visiting Clearview or to a doctor's office. There may be sick people in these areas and we'd like to reduce your exposure to them.
- + surrounded by large crowds (shopping mall, movie theater). You should avoid crowds and do shopping at times when places are less crowded.
- + undecided whether to wear a mask or not.

You should always carry a spare mask in case any unexpected situations arise. You do not have to wear a mask at home or in a hotel room; while riding in a car; when outside, in open spaces.

- You may take Maalox or Mylanta for indigestion or heartburn. If stomach gas is a problem, try an antacid with simethicone.
- You may use Ocean Spray nasal spray for dry nasal passages. (*Do not use Afrin, or any over the counter medicated nasal sprays*).
- You may use "natural tears" for dry eyes.
- Do not smoke cigarettes, cigars, or pipes. It is also important for you to avoid being around those who smoke.
- Do not pump your own gasoline for three months.
- Your transplant physician will determine when you can return to work.

**Notify your transplant team immediately if any of the following develop:**

- Temperature of 100.5 F or higher
- Any signs of infection such as pain with urinating or bowel movement, red or draining Pheres-Flow catheter site, cough, sore throat, nasal congestion, runny nose
- Any dental problems
- Any shortness of breath
- Any new diarrhea or unrelieved constipation, rectal soreness, or abscess
- Any signs of bleeding such as blood in urine, black or tarry stools, new bruises or petechiae, headaches or blurred vision, prolonged nosebleeds, prolonged vaginal bleeding, bleeding gums
- Shaking chills, with or without fever
- Sores on lips, mouth, or genital area
- Unusual vaginal discharge or bleeding, itching
- Vomiting, vomiting blood or "coffee grounds" material
- Infected eyes; ingrown nails.

## Possible Complications Related to PBSCT

A complication in medical terms means something happened that was not planned or intended. Sometimes a complication is expected; sometimes it's unexpected.

Your body uses its immune system to defend itself from anything foreign that tries to get into it. The body will try to reject or get rid of things that are not a usual part of the body, such as a germ that causes an infection or transplanted bone marrow.

Everyone has “good” germs that live in and on our bodies. These germs don't make us sick as long as our immune systems are working normally. However, the “good” germs can make us sick when the immune system isn't working well.

### Infections

After your conditioning chemotherapy, your blood counts will be lowered. When your white blood cells (*WBCs*) are low, your immune system is not working normally and you are at high risk for infections. WBCs are our bodies' defense mechanisms against infections such as bacteria, fungi, or viruses. Normal WBC count is 4,000-11,000. Based on your needs, medicines will be considered to help prevent these infections.

- *An antibiotic to fight infection caused by bacteria.*
- *An antiviral to fight infection caused by viruses.*
- *An antifungal to fight infection caused by fungi.*

If you run a fever greater than 100.5 degrees Fahrenheit while your WBCs are low, your antibiotic will be changed to IV. You will stay in the hospital until your fever is gone and your white blood cells, platelets, and red blood cells are at a safe level.

Infections are major complications of peripheral blood stem cell transplantation. The design of the oncology unit, special procedures for cleaning equipment, and visit control are all aimed at decreasing the probability of your getting infections. The two body areas most susceptible to infections are the mouth and the rectum. You will be given specific directions about special care of these areas. In addition, there are some things you can do to decrease the likelihood of infections. Although special measures such as strict hand washing are used on the oncology unit, many patients still get an infection.

If you get an infection, the doctors will decide which antibiotic is best for you by finding out which germs are causing your infection. This is done by taking a sample of your blood, urine, or mucus in your throat, etc. and identifying the germs growing in the sample. Sometimes germs don't grow, but you still look like you have an infection. To be on the safe side, a doctor will order an antibiotic for you.

Antibiotics are usually given through the Pheres-Flow catheter. The medicine will be given around the clock by the nurses. Some antibiotics have side effects that cause problems for your liver or kidneys. The doctor and nurses will check you very closely to see if these side effects are happening.

- » Careful hand washing is the best way to decrease infections (*You should be able to sing the “Happy Birthday” song twice for adequate hand washing*). You should wash your hands before eating and performing mouth

care. Wash your hands after using the bathroom and handling anything that might be soiled. Ask someone else to pick up anything that drops on the floor. The object should then either be washed or discarded. If you notice that family, visitors, or hospital staff members (*including your doctors*) do not wash their hands, please remind them to do so. The germs that other people have can cause problems with infection.

- » Staying in your hospital room with the special air filtration system is another way to keep you from getting germs from another person. Also wearing a mask when allowed to ambulate in the halls protects you from others' germs.
- » Do not eat raw fruits or vegetables. All food sent by the hospital kitchen should be cooked. If you have questions about whether any food is OK, please ask the nurse or nutritionist.
- » No fresh flowers or plants are allowed in your room because they may carry germs.

**Clearview has provided a list of possible diseases which could result from an infection, however, please note that cases of infection are very rare, and that every care will be taken to protect you from any complications.**

- » **Veno-Occlusive Disease (VOD):** A potentially serious disorder of the liver that is caused by the high doses of chemotherapy. Blood vessels in small veins become blocked and swollen, impairing the liver's ability to do its job of removing drugs and waste products from the body. The liver cells themselves can be damaged also. This is caused by the breakdown of tissue as a result of the chemotherapy used before the transplant. Symptoms of VOD include sudden weight gain; swelling in the arms, legs, and abdomen; jaundice (yellowing of the skin and eyes); abdominal pain (usually in the right-upper part of the abdomen); and confusion.

There is currently no proven treatment for VOD, but if it develops, your PBSCT team will take steps to minimize its effects. In most cases that are mild to moderate, the liver damage is reversible and the liver will completely recover on its own.

- » **Interstitial Pneumonia:** A nonbacterial, nonfungal form of pneumonia that infiltrates the interstitial space of the lungs. It may be caused by a virus or by chemotherapy, and it is most common in the first 100 days after the peripheral blood stem cell transplantation. You will have regular chest x-rays while you are in the hospital, and your PBSCT team will watch you closely for any sign of pneumonia.
- » **Bladder Toxicity:** Hemorrhagic cystitis is a bladder toxicity resulting from a chemotherapy drug called cyclophosphamide (cytoxan). It ranges from microscopic blood in the urine to visible bleeding. To help protect the bladder, a drug called Mesna, a uroprotectant, is given before and during cytoxan therapy. IV hydration will also be given during treatment to help flush cytoxan out of the bladder quickly.

A Foley catheter may be placed in the bladder before cytoxan is given and will remain in place for 72 hours after the completion of the drug. This is for patients who are at high-risk for hemorrhagic cystitis. The catheter will help prevent the drug from sitting in the bladder too long.

If hemorrhagic cystitis occurs, the treatment includes bladder irrigation through a three-way foley catheter to clear developing clots.

- » **Kidney Toxicity:** Kidney damage can occur because many chemotherapy agents are removed from your body through your kidneys. Many of the medicines you take during the entire transplant process cause extra work for your kidneys. This work load and the effect of the transplant process on other body organs can cause kidney problems. The nurses and doctors will keep a close watch on how your kidneys are working. Certain blood tests,

the amount of urine your kidneys put out, and whether or not you gain weight will tell us if your kidneys are working or not.

- » **Heart Toxicity:** Heart complications can develop within several days following administration of high dose chemotherapy. Heart toxicity can usually be managed with fluid balance and medications. Symptoms usually resolve during the first 100 days after transplant. Death from heart toxicity is less than one percent.
- » **Neurological Toxicity:** Some chemotherapy drugs can cause neurological damage resulting in numbness or tingling in the hands and feet. The incidence varies depending on the type of chemotherapy drugs used, prior use of neurological toxic drugs, and the presence of other medical conditions. It may take several months for symptoms to resolve, and it is possible that they never completely will.
- » **Second/Therapy-Related Cancers:** One of the most serious long-term consequences of cancer is that the treatment intended to cure the patient may contribute to the occurrence of a second malignancy. Second malignancy refers to a new cancer that has developed after treatment of the initial cancer. It implies that the new cancer is related in some way to treatment that was not only cytotoxic but also carcinogenic. Although the risk for a secondary cancer is small, treatment for the initial cancer usually outweighs the risk.



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